ALASKA'S EARLY INTERVENTION / INFANT LEARNING PROGRAM

2009 FAMILY OUTCOMES SURVEY

Families of Children Enrolled Between January 1 & December 31, 2008

A Report for the

Early Intervention/Infant Learning Program
Office of Children's Services
Department of Health & Social Services
State of Alaska

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Alaska's Early Intervention / Infant Learning Program 2009 Family Outcomes Survey

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ALASKA'S EARLY INTERVENTION / INFANT LEARNING PROGRAM 2009 FAMILY OUTCOMES SURVEY

Executive Summary

Alaska's Early Intervention /Infant Learning Program (EI/ILP) is under the administration of the Office of Children's Services (OCS) in the Department of Health and Social Services. The EI/ILP oversees an array of flexible early intervention services for children birth to three years of age who have disabilities or developmental delays, or who are at risk for developmental delays. During 2008, services were administered through 17 regional EI/ILP grantees.

The U.S. Department of Education Office of Special Education Programs (OSEP) requires State agencies to develop and implement outcome measures to evaluate infant and toddler programs operated under Part C of the Individuals with Disabilities Education Act (IDEA). The 2009 Family Outcomes Survey asked for family experiences based on five OSEP family outcome areas and their general level of satisfaction with EI/ILP services:

- 1. Families understand their child's strengths, abilities and special needs.
- 2. Families know their rights and advocate effectively for their children.
- 3. Families help their child develop and learn.
- 4. Families have support systems.
- 5. Families access desired services, programs and activities in their community.
- 6. Families are satisfied with the services they received.

The survey protocol used for this evaluation (Appendix A) utilized a revision of the scale first used in 2008, simplifying some wording, resolving compound items, and adding new items. The protocol used the same 4-point Likert scale recommended for improved cultural appropriateness for Alaska's indigenous populations. Families were asked to rate experiences with their children and EI/ILP on 21 statements by choosing how often each statement was true for their family: none of the time, some of the time, most of the time, or all of the time.

The methodology of the 2009 Family Outcomes Survey utilized a randomly selected target group, stratified geographically (by ILP grantee) and comprised of 120 families who received services in 2008. Only those families with children who were eligible for Part C and received services for at least 6 months were eligible to be chosen. The survey and letter of introduction were mailed to the target group of families, inviting them to complete the survey by mail, online, or over the phone. There were 62 completed surveys rendering a 52% response rate.

Characteristics of responding families were compared with the randomly selected target group and the total eligible population of service recipients. Similarity across all three lent increased confidence that as a group, responders could be considered representative of all eligible families receiving ILP services during 2008. Though the target group of families was not stratified by race/ethnicity, there was no indication of an under-representation of families with Native children as there had appeared to be in previous survey years.

It can be concluded from the results of the 2009 survey that there was an overall high level of satisfaction with the EI/ILP services from families receiving Part C services. There were

no significant differences within 2009 responses based on race/ethnicity of children or area of residence.

The greatest outcome area strengths were Outcome 1 regarding caregiver understanding of children, Outcome 5 regarding community access, and Outcome 6 regarding satisfaction with ILP services. There was relatively no change from 2008 to 2009 within Outcome 1, but there were significant increases within both Outcomes 5 and 6. Where these areas saw the most improvements were in opportunities for children to fully participate in community activities (in Outcome 5) and satisfaction with ILPs helping caregivers to know their rights (in Outcome 6).

In Outcome 2 regarding rights and advocacy, there was some indication of improvement from the previous year, especially informing people about rights and services. However, relative to the previous mentioned outcomes, there was room for improvement. Some new items in this area pointed out potential concerns about whether or not people are informed they have a right to choose the services they receive, and whether or not they are asked for consent before records are shared with others. Similarly, parental knowledge about what they can do if they are not satisfied with their services was relatively weaker than other satisfaction items.

Outcome 3, regarding caregiver ability to help children develop and learn, was relatively weaker. These results were similar to those in this outcome area the previous year. Again, caregivers indicated they particularly needed more help in knowing how to improve children's behavior.

Similar to the previous survey year, Outcome 4 regarding social support was a relatively weak area. On the one hand, respondents had a high level of access to people they could talk with any time they wanted. On the other hand, the weakest results of the 2009 survey were in families having people in their lives they could call upon to watch their children for a short time, or people they could call upon for other assistance (e.g., transportation, small repairs, etc.).

There were relative strengths and weaknesses within each outcome area. Item results seemed to logically cluster by strength. For example, there were strengths in caregiver understanding of children's development, ability to detect progress, and knowledge of helping children develop and learn. There were relative weaknesses in understanding children's special needs, knowing how to help children behave, and developing plans with a team. There were strengths in the ability of families to do things they enjoyed, as well as in having opportunities for their children to fully participate in community activities.

Comments added to surveys were largely expressions of gratitude and compliments. In the mixed and negative comments, there was an indication that follow-up and transition from ILPs to preschools and other services had sometimes been problematic. These appeared to be isolated cases. That is, there was no indication these problems were symptomatic of any agency.

Issues to consider:

1. How can caregivers be helped to build natural, mutual systems of assistance within their social networks? If this is not possible, what else can be done to meet basic needs for occasional childcare and other assistance?

- 2. How can opportunities be increased for family involvement in making plans with teams to address children's special needs?
- 3. How can families be more involved in choosing the services they receive?
- 4. How can parents learn more about their children's special needs and how to help their children to be well behaved?
- 5. How can information about advocacy be communicated more effectively, particularly about ways for families to do something if they are not satisfied?
- 6. If the standard is to always obtain parental consent before sharing records with others, how can ILP compliance with the standard be increased?
- 7. Is there a need to focus more attention system-wide on facilitating better transitions to preschool or other services?

Survey Administration:

It is recommended that the Alaska State EI/ILP office continue to use the methodologies employed in the 2008 and 2009 surveys, specifically using a randomly selected target group stratified by ILP grantee, and providing for multiple ways to respond to the survey. Reliance on phone numbers as a means to follow up with non-responders is becoming problematic as it appears more young families are replacing land lines with cell phones. It would be helpful if ILP providers were more careful about making sure they correctly enter phone numbers in the database. Often the last two digits were missing.

An unrelated research project looking at the impact of CAPTA on the EI/ILP system in Alaska discovered a big discrepancy between data about Native race/ethnicity entered in the EI/ILP database and data entered on the same children in the child protection system. It has been suggested the EI/ILP implement procedures to ensure accurate reporting on this variable. In light of this finding, it seemed the best way to ensure Native representation in the 2009 Family Outcomes Survey was to rely strictly on the random selection process. In this year's survey, available evidence suggested there was appropriate Native representation among respondents.

The survey instrument is becoming more refined. One remaining drawback may be the 4-point Likert scale. A more robust approach is to use an interval scale where only the end-points are labeled. For example, using the same language as the current scale, this would mean the end-points might be "none of the time" and "all of the time." Between these two extremes there could be any number of unlabeled points where a respondent could indicate where they fall between the two extremes. It is worth asking ILP service providers with Native heritage if an interval scale makes any sense in the context of indigenous cultures, and if there is any particular way to present such a scale that would make it more understandable.

ALASKA'S EARLY INTERVENTION / INFANT LEARNING PROGRAM 2009 FAMILY OUTCOMES SURVEY

Introduction

Since reorganization of State government in fiscal year 2004, Alaska's Early Intervention /Infant Learning Program (EI/ILP) has been under the administration of the Office of Children's Services (OCS), along with Early Childhood Comprehensive Systems Planning, Child Protection and Permanency, and Family Nutrition Services. OCS is under the State's Department of Health and Social Services. OCS has an overall mission to "enhance families' capacities to give their children a healthy start, to provide them with safe and permanent homes, to maintain cultural connections, and to realize their potential."

Under this organizing vision, the EI/ILP oversees an array of flexible early intervention services for children birth to three years of age who have disabilities or developmental delays, or who are at risk for developmental delays. In 2008 services were provided in communities across the state by 19 local provider agencies: 17 regional EI/ILP grantees, as well as 2 statewide consultant programs for vision and hearing. EI/ILP grantees included school districts, mental health associations, Native corporations, parent associations, and other nonprofit organizations. Services included developmental screening and evaluation; individualized family service plans; home visits; physical, occupational, and speech therapies; and mental health services for children. Service providers shared assessment, development, and intervention information and strategies with families, dealt with specialized equipment, and made appropriate referrals to meet child and family needs beyond the scope of their programs.

EI/ILP funding came from multiple sources including State general funds, federal Part C funds, Medicaid, and billing receipts from insurance and other third party payers. EI/ILP activity and progress are reported to the U.S. Department of Education Office of Special Education Programs (OSEP). OSEP requires State agencies to develop and implement outcome measures to evaluate infant and toddler programs operated under Part C of the Individuals with Disabilities Education Act (IDEA). Through a developmental process of working with experts and meeting with stakeholders, OSEP identified five family outcome areas. Guided by this framework, Alaska's annual EI/ILP Family Outcomes Survey is an effort to gather this type of information from the perspective of families in Alaska who have received EI/ILP services, along with their general level of satisfaction with the EI/ILP services provided:

- 1. Families understand their child's strengths, abilities and special needs.
- 2. Families know their rights and advocate effectively for their children.
- 3. Families help their children develop and learn.
- 4. Families have support systems.
- 5. Families access desired services, programs and activities in their community.
- 6. Families are satisfied with the services they received.

Methodology

Historically, through a series of stakeholder meetings, the protocol chosen by the EI/ILP to survey families by OSEP outcomes in 2006 (2005 service recipients) was the Early Childhood Outcomes (ECO) Center's tool, the *ECO Family Outcomes Survey*. The ECO Center is funded by OSEP to provide leadership and assistance to state-level government agencies in their efforts to collect and report child outcome data. In 2007 (2006 service recipients), the EI/ILP chose to use the same instrument and employed a census approach (i.e., sending one survey per each child who received any ILP services in the targeted year).

The evaluators of the 2007 survey found a number of potential problems with the quality of information gathered in 2007 and recommended greatly simplifying the instrument along with a series of methodological changes, which were subsequently approved by OSEP for the 2008 survey. These included making the family the unit of measurement (rather than the child) and randomly selecting a segment of the population to receive the survey (rather than using a census approach).

For the 2009 survey, EI/ILP made several revisions to the 2008 survey items. Some items were the same content, but worded more simply or succinctly. One compound item (i.e., asking for one response to two different things) was split into two items. For three other compound items, only one part of the item was retained. Two new items were added. These changes impose limitations on the comparisons that can be made between the 2008 and 2009 survey results.

A third-party evaluator, the University of Alaska Anchorage Center for Human Development (CHD), was contracted to implement the 2009 survey of families with children who had received EI/ILP services from January 1 to December 31, 2008. A target group of 120 families was randomly selected from those including at least one child who not only received services in 2008, but was also eligible for Part C and had been enrolled in the program for at least 6 months.

Families were asked to rate experiences with their children and EI/ILP on 21 statements by choosing how often each statement was true: none of the time, some of the time, most of the time, or all of the time. This 4-point Likert scale was recommended to the EI/ILP by a group of indigenous providers who had consulted as a group about making survey instruments more culturally appropriate for Alaska's indigenous cultures. The 2009 EI/ILP invitational letter and Family Outcomes Survey instrument are included with this report in Appendix A.

Information about children and families was pulled from the EI/ILP statewide database system. There were 705 children who met selection criteria to be included in the 2009 survey, 124 more than those eligible for the previous year's survey. Of these, 120 families stratified by the 17 grantees were randomly selected using an online calculator (www.randomizer.org, Urbianak & Plous, 1997) to serve as the target group. Survey packets containing the invitational letter, the survey instrument, and a postage-paid return envelope were mailed to families in the target group the week of March 10, 2009. Ten mailed out surveys were soon returned as undeliverable. These families were each immediately replaced with the next available family on the list from the same region, and packets were mailed out to these replacement families. There were 128 children who received EI/ILP services among the 120 families in the final target group.

The letter accompanying surveys invited families to complete the survey by mail, online, or by using a toll-free phone number, and informed them that evaluators would contact them in about two weeks if their survey had not been completed. When evaluators called non-responding families, they invited caregivers to complete the survey over the phone or online, and honored requests to opt out or to have the survey resent by mail. Having a phone number was not an eligibility requirement for inclusion in the target group. A phenomenon not apparent in previous years, was that a larger number of caregivers in 2009 seemed to have only cell phones. This made phone calling less productive as a follow up strategy. When there were errors or non-working phone numbers in the EI/ILP database, a frequent occurrence, only a small proportion of numbers could be found through phone directory resources. When non-responding families could not be reached directly by phone for any reason, a postcard reminder was sent to them by mail, including the toll-free phone number and online address to access the survey.

Potential participants were offered the incentive of being entered into a drawing to give away ten \$25 gift cards to a choice of three popular shopping venues. The evaluators used the same online random sampling calculator (www.randomizer.org, Urbianak & Plous, 1997) to identify 10 winners from among those who responded to the survey.

The analyses of data for this report were primarily descriptive statistics (frequencies, distributions, and measures of central tendency). A one-way ANOVA was used to determine if there were any indications of significant patterns in responses based on areas of residence. When it appeared responses were different between 2008 and 2009, these responses were compared using independent, 2-tailed t-tests. Equal variances were assumed unless indicated otherwise.

Regarding race/ethnicity, typically the largest proportion of children are identified as White and the second largest proportion are identified as American Indian or Alaska Native, with little representation on any other race/ethnicity. In last year's survey sample, it appeared as if families including children with Native heritage had been under-represented in both the target group and in responders. It was recommended to stratify the target group on this variable. However, independent of this survey, the evaluator had an opportunity to examine child protection data and EI/ILP data on a single group of children. While about half were Native in child protection data, closer to a quarter of the same children were Native in EI/ILP data. It was evident that ILP providers very often indicated "other" for race/ethnicity. Due to questionable reliability of data on this variable, the 2009 Family Outcomes Survey target group was not stratified by race/ethnicity. Theoretically, randomization alone was a better assurance of representation on this variable. However, there was a sizeable group of children among responding families who were identified as American Indian or Alaska Native. Independent, 2-tailed t-tests were used to determine if there were any significant differences between these responses and those of families with White children.

Comments added to surveys by respondents fell into general categories based on being positive, negative, or mixed positive/negative. A discussion of comments is at the end of the Results section. De-identified comments are listed in Appendix B.

Results

Sixty-two (n = 62) surveys were completed by families for a response rate of 52%. The randomly selected target group was stratified by grantee to increase probability of geographic representation among responders, which should also encompass urban and rural residents. The number of families in the target group from each grantee service provider was based on the grantee service population's percent of the total number of families eligible to be included. That is, the percent in the target group (n/120) was as close as possible to the same percent in the total number of eligible families (n/705). Below are details about the response followed by Table 1 showing the number and proportion of responses sorted by the four OCS regional service areas.

Target Population (with replacement families)	120
Made contact (mail not returned)	120
Ineligible	0
Opted out or did not respond (O)	58
Eligible completed surveys (S)	62
No contact (N)	0
Response Rate = $S / (S + O + N) = 0.516$ or 52%	

Table 1: Response sorted by OCS service areas

	OCS Service Area	Community Agencies (EI/ILP Grantee)	Sent	Rec'd	(%)
1	Northern Region	Project TEACH (ACC) Early Learning & Family Program (NWA) Norton Sound Health Corp ILP (NSH) Tanana Chiefs Conference ILP (TCC) Yukon-Kuskokwim Health Corp Family Infant Toddler Program (YKH)	28	16	57.1
2	Anchorage Region	Programs for Infants & Children (PIC)	42	22	52.4
3	Southcentral Region	Valdez ILP (ACC) Copper River ILP (ACC) Bristol Bay Area Health Corp ILP (BBA) FOCUS ILP (FOC) Frontier Community Services ILP (FCS) Birth 2 Three (HCS) Kodiak ILP (KAN) Mat-Su Infant Learning Program (MSU) SeaView Community Services ILP (SVC)	29	15	51.7
4	Southeast Region	Center for Community Early Learning Program (CFC) Community Connections Early Learning Program (CCK) REACH ILP (REA) SERRC's ILP (SER)	21	9	42.9

TOTAL: 120 62 51.7

Response was fairly well spread across OCS service areas of the state. The lowest response rate by region was in the Southeast Region, at about 9% below the average. However, the numbers are so small that only two more responses would have pulled the Southeast Region equal to the average. Breaking the data down to responses from agencies results in numbers that are even smaller and less meaningful, but Table 2 shows this breakdown.

Table 2: Response sorted by grantees

	Grantee (EI/ILP Code #)	Community Agencies	Sent	Rec'd	(%)
1	Alaska Center for Children & Adults (ACC)	Project Teach, Valdez ILP, and Copper River ILP	17	10	58.8
2	Bristol Bay Area Health Corporation (BBA)	Bristol Bay Area Health Corporation ILP	2	2	100
3	Center for Community (CFC)	Center for Community ILP	2	0	0
4	Community Connections (CCK)	Community Connections Early Learning Program	7	3	42.9
5	FOCUS (FOC)	FOCUS ILP	7	2	28.6
6	Frontier Community Services (FCS)	Frontier Community Services ILP	4	3	75
7	Homer Children's Services (HCS)	Birth 2 Three	2	1	50
8	Kodiak Area Native Association (KAN)	Kodiak ILP	1	1	100
9	Mat-Su Services for Children & Adults (MSU)	Mat-Su ILP	11	5	45.5
10	Northwest Arctic School District (NWA)	Early Learning & Family Program (ELF)	1	0	0
11	Norton Sound Health Corporation (NSH)	Norton Sound Health Corporation ILP	2	1	50
12	Programs for Infants & Children (PIC)	Programs for Infants & Children (PIC)	42	22	52.4
13	REACH, Inc. (REA)	REACH ILP	11	5	45.5
14	SeaView Community Services (SVC)	SeaView Com. Svcs. ILP	1	1	100
15	SERRC – Alaska Education Resource Center (SER)	SERRC's ILP	1	1	100
16	Tanana Chiefs Conference (TCC)	Tanana Chiefs Conf. ILP	2	0	0
17	Yukon-Kuskokwim Health Corporation (YKH)	YKHC Family Infant Toddler Program (FIT)	7	5	71.4
		TOTAI	. 120	62	517

TOTAL: 120 62 51.7

Within regions and sometimes within agencies, both urban and rural populations were served. If responding families with mailing addresses in Anchorage, Eagle River, Fairbanks, and Juneau are defined as the urban families, they represent 54.8% of all responding families. While there was a higher urban response (i.e., > 50%), it is not enough to cause undo concern. In terms of regions and types of communities, it appears respondents comprised a sample that can be considered representative of the population of Alaskan families eligible for this survey.

Demographics of Responding Families

The State EI/ILP collects data on race/ethnicity of the child, which may or may not be the same as race/ethnicity of caregivers. For example, it is not uncommon for children in foster care to receive ILP services. Therefore, the "race/ethnicity of families" cannot be assumed from this data.

Among the 62 families who responded to the survey there were 65 children who met the criteria for their families to be included in this sample. The ethnicity of the majority of children was indicated as White/Caucasian (43%) followed by Alaska Native or American Indian (32%). Together, these two race/ethnic categories included children in 47 families, or 76% of the responders. Other indications of race/ethnicity were Other (14%), Hispanic or Latino (6%), and Asian or Pacific Islander (5%).

Table 3 shows a comparison of the ethnicity of children across the families who responded to the survey, those in the randomly selected target group, and the total population of children who were eligible for the survey (Part C and enrolled at least 6 months). Remember that the number of children in the following tables exceeds the number of families. Reported percents are rounded up, and thus they do not necessarily add up to exactly 100%.

Table 3: Ethnicity of children in responding families compared to the randomly selected target group and the total eligible survey population

Ethnicity of Children	Respo	ponders Target Group		<u>Eligible</u>		
Ethnicity of Children	n	%	n	%	n	%
AK Native or Am. Indian	21	32.3	41	32.0	204	28.9
Asian or Pacific Islander	3	4.6	7	5.5	26	3.7
Black/African American			2	1.6	23	3.3
Hispanic or Latino	4	6.2	7	5.5	26	3.7
White/Caucasian	28	43.1	52	40.6	293	41.6
Other	9	13.8	19	14.8	133	18.9
Totals	6	5	12	28	70)5

All families included in the 2009 survey had one or more children enrolled in EI/ILP services and qualified for Part C services. Table 4 shows a comparison of the qualifying categories of children across the families who responded to the survey, those in the randomly selected target group, and the total population of families who were eligible. Across all three, the reason most children qualified for Part C services was a documented delay of over 50%, which has consistently been true in previous survey years.

Table 4: How children in responding families qualified for services compared to the target group and the total eligible survey population

Qualifying Category	Respo	Responders Target Group		<u>Eligible</u>		
Qualifying Category	n	%	n	%	n	%
A: Part C Diagnosis	10	15.4	21	16.4	161	22.8
B: Delays > 50%	48	73.8	88	68.8	445	63.1
C: Clinical Opinion	7	10.8	19	14.8	96	13.6
Other					3	0.4
Totals	6	5	12	28	70)5

Within responding families, 32 (49.2%) children were still enrolled in the program at the end of 2008, and 33 (50.8%) had exited the program sometime during the year. This compares to the target group with 67 (52.3%) enrolled and 60 (46.9%) exited; and the total eligible child population with 382 (54.2%) enrolled and 320 (45.4%) exited. These latter number do not add up exactly because there were a few children whose enrollment status was noted as something other than enrolled or exited, such as unknown, declined, or lost. The enroll/exit figures indicate the survey sample, target group, and eligible population were all fairly similar on this variable. This is different than previous survey years when the response was proportionately lower from families who had exited from the program.

Of the children among the responders, as well as those in the target group and the eligible population who exited in 2008, the exit reason given for about 20% was "Part B eligible," indicating they had aged out of Part C services, but were still qualified to receive services under Part B of IDEA. The distribution of exit reasons was fairly similar across the survey sample, target group, and eligible population (Table 5).

Table 5: Reasons families exited the program in 2008

Exit Reason	Responders	Target Group	Eligible
Part B eligible	13 (20%)	23 (18%)	149 (21%)
Attempts to contact unsuccessful	3	10	39
Withdrawal by parent/guardian	2	2	30
Moved out of state	1	6	21
Completion of IFSP prior to age 3	5	7	23
Part B eligibility not determined	3	5	25
Not Part B eligible, exit with no referrals	3	3	11
Not Part B eligible, exit to other program	2	2	14
Other Aged Out	1	2	2
Deceased			1
Not Indicated			5
Total Exited	33	60	320

In all three groups, the exit placement was most often in preschool special education (about 40%) followed by placement in the home (about 32%). Together, these accounted for about 72% of all placements. The distribution was fairly similar across respondents, the target group, and the eligible population (Table 6).

Table 6: Exit placements of families who left the program in 2008

Exit Placement	Respondents	Target Group	Eligible
Preschool Special Education	13 (39%)	23 (38%)	134 (42%)
Home	11 (33%)	20 (33%)	99 (31%)
Head Start	2	2	9
Child Care/Preschool	2	2	23
In-State EI/ILP Transfer			1
Outpatient Therapy			6
Other Setting		2	13
Not Indicated	5	11	35
Total Exited	33	60	320

Summary of Respondent Characteristics

Characteristics of responding families were similar to those in both the target group (stratified random selection) and the total eligible population in terms of geographic distribution, race/ethnicity of children, how children qualified for services, enrollment status, and exit placement. Unlike previous survey years, there was no evidence of under-representation of families with Native children or of a lower response from families with children who had exited the program.

Responses to Survey Questions

The total number of responses can naturally vary in the tables that follow for each survey item because respondents could choose not to answer certain items. As percentages are rounded to the first decimal point, percentages of responses do not necessarily add up to exactly 100%.

Generally, ratings on the survey instrument averaged about 3.40 on a 1 to 4 scale. That is, overall, caregivers were confident in their knowledge and abilities, available resources served their needs better than most of the time, and they were predominantly satisfied with the ILP services they had received during 2008.

No differences by race/ethnicity were detected, that is, all statistical tests of responses based on this variable determined that differences were not significant. Similarly, all tests of differences by area of residence were also not significant. Following is an examination of item responses organized by the OSEP Family Outcomes.

Outcome 1. Understanding the child. Items 1-3 on the survey asked respondents to indicate how often they understood their children's development, special needs, and progress. Combining results from these three items (M = 3.45), respondents as a group indicated a high, overall level of understanding in this outcome area. The lowest item response was in

understanding their children's special needs (M = 3.27), but even so, 87% of respondents indicated they understood most or all of the time. The response in Outcome 1 is very similar to the response in this outcome area in the previous year's survey.

Item 1: Our child is growing and learning, and we understand our child's development very well.

Rating	Frequency	Percent	Central Tendency
1 – None of the time			Mean: 3.52
2 – Some of the time	4	6.5	Median: 4.00
3 – Most of the time	22	35.5	Mode: 4
4 – All of the time	36	58.1	SD: .620
Total Responses	62	100	

The response on item 1 indicated that a high 94% of responding families felt they understood their child's development very well, all or most of the time. Well over half (58%) indicated they always understand it very well. The response on this item appeared to be higher than last year's response, but the difference was not significant: t(120) = 1.216, p = .227, ns.

Item 2: We know most of what we need to know about our child's special needs.

Rating	Frequency	Percent	Central Tendency
1 – None of the time	1	1.6	Mean: 3.27
2 – Some of the time	7	11.3	Median: 3.00
3 – Most of the time	28	45.2	Mode: 3
4 – All of the time	26	41.9	SD: .728
Total Responses	62	100	

The response on item 2 indicated that 87% of responding families felt they knew what they needed to know about their children's special needs most of the time (45.2%) or all of the time (41.9%). About 13% indicated they knew only some or none of the time. There was a similar response pattern on this item in the 2008 survey.

Item 3: We can tell if our child is making progress.

Rating	Frequency	Percent	Central Tendency
1 – None of the time			Mean: 3.56
2 – Some of the time	3	4.8	Median: 4.00
3 – Most of the time	21	33.9	Mode: 4
4 – All of the time	38	61.3	SD: .590
Total Responses	62	100	

A high 95% of respondents indicated on item 3 that they could tell when their children were making progress, all of the time (61.3%), or most of the time (33.9%). Here again, the response on this item appeared to be higher than last year's response, but the difference was not significant: t(120) = 1.707, p = .090, ns.

Outcome 2. Rights and advocacy. Items 4-8 asked respondents to indicate how much they knew about their rights and their capacity to advocate effectively on behalf of their children. There were five items in this outcome area in the 2009 survey, 2 more than there were in the 2008 survey. Combining results from the five items (M = 3.39), respondents as a group indicated they were somewhat less confident in this outcome area overall than they were in Outcome 1. Two individual items were rated higher than the other three: being comfortable in meetings (M = 3.60) and giving consent before records are shared (M = 3.48). Respondents had the most difficulty in this outcome area with knowing what to do if they were not satisfied (M = 3.24), but 81% indicated they knew what to do most or all of the time. Comparing this outcome area between 2008 and 2009 was problematic, mostly due to the discrepancy in the number of items. With that caveat in mind, the response on Outcome 2 in 2009 appeared to be higher.

Item 4: We are fully informed about the programs and services that are available for our child and family.

Rating	Frequency	Percent	Central Tendency
1 – None of the time	2	3.2	Mean: 3.30
2 – Some of the time	9	14.5	Median: 4.00
3 – Most of the time	19	30.6	Mode: 4
4 – All of the time	31	50.0	SD: .843
Total Responses	61	98.4	
Missing Data	1	1.6	

The response on item 4 indicated that about 81% of responding families felt they were informed about programs and services all of the time (50.0%) or most of the time (30.6%). There was a notable 18% indicating they were informed only some or none of the time. There was a higher response on this item as compared to last year's survey. For example, 4-level ratings were higher by 20.6 percentage points. The mean difference between the two years was .31 points, and this difference was statistically significant: t(119) = 2.15, p = .034.

Item 5: We have been asked to give consent before anything from our Early Intervention records is shared with others.

Rating	Frequency	Percent	Central Tendency
1 – None of the time	6	9.7	Mean: 3.48
2 – Some of the time	4	6.5	Median: 4.00
3 – Most of the time	6	9.7	Mode: 4
4 – All of the time	46	74.2	SD: .987
Total Responses	62	100	

Item 5 was a new item in the 2009 survey. The State EI/ILP staff added this item to seek caregiver response on this specific family right, and it may be that this response verifies a concern. It is encouraging that about three quarters (74.2%) of responding families indicated they were always asked to give consent before anything from their records was shared with others. A worrisome 26% indicated they were not always asked for consent, with almost 10% indicating they were never asked.

Item 6: We have been informed of our right to choose which Early Intervention services we receive.

Rating	Frequency	Percent	Central Tendency
1 – None of the time	4	6.5	Mean: 3.32
2 – Some of the time	9	14.5	Median: 4.00
3 – Most of the time	12	19.4	Mode: 4
4 – All of the time	37	59.7	SD: .954
Total Responses	62	100	

Item 6 was also new in the 2009 survey. About 79% of responding families indicated they were informed of their right to choose services all or most of the time. Almost 60% indicated they were informed all of the time. There was a notable number of families (21%) indicating they were informed only some or none of the time.

Item 7: We are comfortable participating in meetings with professionals to plan services or activities for our child.

Rating	Frequency	Percent	Central Tendency
1 − None of the time	1	1.6	Mean: 3.60
2 – Some of the time	5	8.1	Median: 4.00
3 – Most of the time	12	19.4	Mode: 4
4 – All of the time	44	71.0	SD: .712
Total Responses	62	100	

On item 7, about 90% of respondents indicated they were comfortable participating in meetings all or most of the time. A high 71% indicated they were comfortable in meetings all of the time. The response on this item appeared to be higher than last year's response, but the difference was not significant: t(120) = 1.001, p = .319, ns.

Item 8: We know what to do if we are not satisfied with any part of our child's program and services.

Rating	Frequency	Percent	Central Tendency
1 – None of the time	4	6.5	Mean: 3.24
2 – Some of the time	8	12.9	Median: 3.50
3 – Most of the time	19	30.6	Mode: 4
4 – All of the time	31	50.0	SD: .918
Total Responses	62	100	

The response on item 8 indicated that about 81% of responding families knew what to do if they were not satisfied, all of the time (50.0%), or most of the time (30.6%). That left a notable 19% who knew what to do only some or none of the time. The content of this item in the 2009 survey was one aspect of a compound item in 2008. The disparity in wording between 2008 and 2009 is too great for any meaningful comparison of response patterns.

Outcome 3. Help child develop and learn. Items 9-11 on the survey asked respondents to indicate how well they knew how to help their children develop, behave, and learn new skills. The combined average response (M = 3.25) indicated somewhat less confidence overall in this

outcome area than what was indicated in most other outcomes. Looking at individual items, there was the most difficulty with helping children learn to behave (M = 3.13), followed by working with professionals to make plans (M = 3.26). There was a similar response in this outcome area in last year's survey.

Item 9: We are sure we know how to help our child develop and learn.

Rating	Frequency	Percent	Central Tendency
1 – None of the time			Mean: 3.37
2 – Some of the time	4	6.5	Median: 3.00
3 – Most of the time	31	50.0	Mode: 3
4 – All of the time	27	43.5	SD: .607
Total Responses	62	100	

A high 94% of respondents indicated on item 9 that they were sure they knew how to help their children develop and learn, most of the time (50.0%), or all of the time (43.5%). This higher level of response is similar to items in Outcome 1 that were relevant to children's development. The response on this item appeared to be higher than last year's response, but the difference was not significant: t(120) = 0.601, p = .549, ns.

Item 10: We are sure we know how to help our child learn to behave.

Rating	Frequency	Percent	Central Tendency
1 – None of the time	2	3.2	Mean: 3.13
2 – Some of the time	8	12.9	Median: 3.00
3 – Most of the time	32	51.6	Mode: 3
4 – All of the time	20	32.3	SD: .757
Total Responses	62	100	

About 84% of respondents indicated on item 10 that they were sure they knew how to help their children learn to behave, most of the time (51.6%), or all of the time (32.3%). About 16% indicated they were sure only some or none of the time. There was a similar response pattern on this item in the 2008 survey.

Item 11: Our family has worked with professionals to develop a plan to help our child learn new skills.

Rating	Frequency	Percent	Central Tendency
1 – None of the time	6	9.7	Mean: 3.26
2 – Some of the time	5	8.1	Median: 4.00
3 – Most of the time	18	29.0	Mode: 4
4 – All of the time	33	53.2	SD: .974
Total Responses	62	100	

About 82% of responding families indicated on item 11 that they worked with professionals to develop a plan all or most of the time. Over half (53.2%) indicated they did this all of the time. A notable 18% indicated they did this only some or none of the time. The content of this item in the

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2009 survey was one aspect of a compound item in 2008. The disparity in wording between 2008 and 2009 is too great for any meaningful comparison of response patterns.

Outcome 4. Support systems. Items 13-16 on the survey asked respondents to indicate their level of resources for emotional support, assistance from others, and ability to do activities the family enjoys. One compound item in this area from the 2008 survey was split into two items for the 2009 survey, making it comprised of 4 rather than 3 items. The combined average response (M = 3.13) on this set of items was the lowest of all outcome areas, indicating that families may have needed relatively more help building social network resources. Respondents seemed to have people to talk with (M = 3.52) and could do activities they enjoyed (M = 3.40), but having help to watch children (M = 2.80) or other assistance (M = 2.81) was lacking.

Item 13: There are people we can talk with any time we want to help us deal with problems or celebrate when good things happen.

Rating	Frequency	Percent	Central Tendency
1 – None of the time	1	1.6	Mean: 3.52
2 – Some of the time	5	8.1	Median: 4.00
3 – Most of the time	17	27.4	Mode: 4
4 – All of the time	39	62.9	SD:.718
Total Responses	62	100	

About 90% of responding families indicated there were people they could talk with to deal with problems or celebrate good things all or most of the time. Almost 63% indicated they had this type of social/emotional support all of the time. There appeared to be a slightly higher response than last year's survey, but it was not significant: t(120) = 0.259, p = .796, ns.

Item 14: We have people we can call on for help when we need someone to watch our child for a short time.

Rating	Frequency	Percent	Central Tendency
1 – None of the time	10	16.1	Mean: 2.80
2 – Some of the time	11	17.7	Median: 3.00
3 – Most of the time	8	12.9	Mode: 4
4 – All of the time	21	33.9	SD: 1.195
Total Responses	50	80.6	
Missing Data	12	19.4	

Item 14 and 15 in the 2009 survey was a single, compound item in the 2008 survey. There was high missing data on item 14 because there was an error in the mailed out survey that rendered mailed in responses unusable. Evaluators called those who responded by mail to ask this single question, but 12 of those families did not have a correct, listed, or working phone number. Caregivers who responded to the survey online or by phone received the correct item.

Percentages in the above table take into account 19% missing data out of 62 possible responses. If the percentages are figured only on the responses received (n = 50), it is probably a more accurate representation of the response pattern on this item. However, the non-listed or non-

working phone number is a selection bias that reduces confidence in the results on this item. Below are the proportions of responses excluding the missing data.

Rating	Frequency	Percent	Central Tendency
1 – None of the time	10	20.0	Mean: 2.80
2 – Some of the time	11	22.0	Median: 3.00
3 – Most of the time	8	16.0	Mode: 4
4 – All of the time	21	42.0	SD: 1.195
Adjusted Total Responses	50	100	

There was a much lower response pattern among the 50 families answering item 14. While well over half (58%) indicated they had people they could call upon to watch their children within their social network all or most of the time, a worrisome 42% indicated they had access to this social resource sometimes or never. A notable 20% indicated never having this resource.

Item 15: We have people we can call on to help us with things other than childcare (e.g., transportation, shopping, or small repairs).

Rating	Frequency	Percent	Central Tendency
1 – None of the time	13	21.0	Mean: 2.81
2 – Some of the time	11	17.7	Median: 3.00
3 – Most of the time	13	21.0	Mode: 4
4 – All of the time	25	40.3	SD: 1.185
Total Responses	62	100	

Interestingly enough, the response pattern on item 15 was almost identical to the response pattern on item 14. Well over half (61.3%) of responding families indicated they had assistance with things other than childcare in their social network all or most of the time, and close to 40% had access to this resource sometimes or never. Again, there was a notable group (21%) indicating they never had this resource. The response patterns on both items 14 and 15 were similar to the response pattern on the compound item in last year's survey.

Item 16: We are able to do the activities our family enjoys.

Rating	Frequency	Percent	Central Tendency
1 – None of the time			Mean: 3.40
2 – Some of the time	6	9.7	Median: 3.50
3 – Most of the time	25	40.3	Mode: 4
4 – All of the time	31	50.0	SD: .664
Total Responses	62	100	

On item 16, caregivers who felt they could do activities their families enjoyed, most of the time (40.3%), or all of the time (50%) comprised 90% of responding families. In 2008 this item read, "We are able to do *almost all* the activities our family enjoys" (italics added). The impact of the wording may be different enough to call for caution in interpreting the difference in response between the two years. With that caveat in mind, the response was higher in 2009. The mean difference between the two years was .35 points, and this difference was statistically significant: t(120) = 2.558, p = .012.

Outcome 5. Community access. Items 17-19 on the survey asked respondents to indicate their level of access to desired services, programs, and activities in the community. Combining results from these three items, the average response (M = 3.49) indicated that responding families as a whole tended to have access to high quality medical care (M = 3.60) and community activities (M = 3.57), with somewhat less access to childcare (M = 3.31). There was a somewhat higher response in this outcome area as compared to last year.

Item 17: We have excellent medical care for our child.

Rating	Frequency	Percent	Central Tendency
1 – None of the time			Mean: 3.60
2 – Some of the time	6	9.7	Median: 4.00
3 – Most of the time	13	21.0	Mode: 4
4 – All of the time	43	69.4	SD: .664
Total Responses	62	100	

Close to 70% percent of responding families on item 17 indicated they always had excellent medical care for their children and 21% indicated they had it most of the time, for 90% combined. While almost 10% indicated access only some of the time, all families had some access to excellent medical care. There was a similar response pattern on this item in 2008.

Item 18: We have excellent childcare for our child.

Rating	Frequency	Percent	Central Tendency
1 – None of the time	4	6.5	Mean: 3.31
2 – Some of the time	9	14.5	Median: 4.00
3 – Most of the time	12	19.4	Mode: 4
4 – All of the time	36	58.1	SD: .958
Total Responses	61	98.4	
Missing Data	1	1.6	

On item 18, almost 78% of responding families indicated they had excellent childcare, all (58.1%), or most (19.4%) of the time. A notable 22% had this resource sometimes or never. There was a similar response pattern on this item in the 2008 survey.

Item 19: Our child has opportunities to fully participate in activities in the community (e.g., playing with others, social or religious events).

Rating	Frequency	Percent	Central Tendency
1 − None of the time	1	1.6	Mean: 3.57
2 – Some of the time	2	3.2	Median: 4.00
3 – Most of the time	19	30.6	Mode: 4
4 – All of the time	39	62.9	SD: .644
Total Responses	61	98.4	
Missing Data	1	1.6	

With about 63% of responding families indicating on item 19 that their child had opportunities to fully participate in community activities all of the time, and almost 31% indicating most of the

time, a high 94% fell in these two response categories. This is what made the improvement seen in this outcome area from last year's survey. For example, the combined 3- and 4-level ratings were 25.4 percentage points higher; 4-level ratings were 19.4 percentage points higher. The mean difference between the two years was a very high .44 points. The significance of this difference was particularly dramatic: t(104) = 3.025, p = .003 (equal variances not assumed).

Outcome 6. Satisfaction with EI services. Item 12 consisted of the statement, "Early intervention has done an excellent job..." followed by three unnumbered sub-items asking respondents to indicate the quality and effectiveness of ILP services they received in three topical areas. Combining results, a high average response (M = 3.48) indicated that responding families as a whole were satisfied with EI services. There was a slightly higher response in this outcome area as compared to last year's survey.

Item 12.1: Early Intervention has done an excellent job helping us know our rights.

Rating	Frequency	Percent	Central Tendency
1 – None of the time	2	3.2	Mean: 3.48
2 – Some of the time	5	8.1	Median: 4.00
3 – Most of the time	16	25.8	Mode: 4
4 – All of the time	39	62.9	SD: .784
Total Responses	62	100	

Almost 89% of responding families indicated EI had done an excellent job helping them know their rights, all or most of the time. About 63% indicated this was true all of the time. There was a higher response on this item as compared to last year's survey. For example, 4-level ratings were higher by 22.3 percentage points. The difference between the two survey years was statistically significant: t(120) = 1.982, p = .050.

Item 12.2: Early Intervention has done an excellent job helping us effectively communicate our child's needs.

Rating	Frequency	Percent	Central Tendency
1 – None of the time	1	1.6	Mean: 3.45
2 – Some of the time	4	6.5	Median: 4.00
3 – Most of the time	23	37.1	Mode: 4
4 – All of the time	34	54.8	SD: .694
Total Responses	62	100	

About 92% of responding families indicated EI had done an excellent job helping them effectively communicate their children's needs, all or most of the time. About 55% indicated this was true all of the time. There was a fairly similar response pattern on this item in the 2008 survey.

Item 12.3: Early Intervention has done an excellent job helping us help our child develop and learn.

Rating	Frequency	Percent	Central Tendency
1 – None of the time	1	1.6	Mean: 3.52
2 – Some of the time	6	9.7	Median: 4.00
3 – Most of the time	14	22.6	Mode: 4
4 – All of the time	40	64.5	SD: .744
Total Responses	61	98.4	
Missing Data	1	1.6	

About 87% of responding families indicated EI had done an excellent job helping them help their children develop and learn, all or most of the time. About 65% indicated this was true all of the time. There was a fairly similar response pattern on this item in the 2008 survey.

Overall Satisfaction with EI/ILP Services

Overall, satisfaction with EI/ILP services can be considered high, with a clear majority of caregivers noting they were satisfied most, if not all of the time (87% to 92%). Between the responders in 2008 and 2009, there was a significant increase in satisfaction with ILPs helping families know their rights. Below is the average response on the three satisfaction items for each OCS region. All tests for differences among responses based on areas of residence were insignificant.

Table 7: Satisfaction by OCS area (combined average response on item 12.1-12.3)

Region	n	M
Northern Region: ACC (Fairbanks), NWA, NSH, TCC, & YKH	16	3.67
Anchorage Region: PIC	21	3.33
Southcentral Region: ACC (Copper River & Valdez), BBA, FOC, FCS, HCS, KAN, MSU, SVC	15	3.67
Southeastern Region: CFC, CCK, REA, SER	9	3.33
Total	61	3.50

Note: The number of responses may not exactly equal the number of respondents reported earlier because respondents could choose not to answer some questions.

Discussion of Comments Added to Surveys

The second page of the EI/ILP 2008 Family Outcomes Survey instrument invited caregivers to make comments. Thirty-four (34) caregivers or 55% of respondents added comments to their surveys. Some comments are included in this discussion as examples; all comments are listed in Appendix B. Because researchers at the Center for Human Development have a responsibility to protect the identities of survey respondents, reasonable measures were taken to remove identifying information from comments included in this report by replacing it with generic terms in brackets. For example, information that could lead back to the identity of a respondent included names of respondents, children, service providers, programs, and areas of residence.

Expressions of gratitude and satisfaction. Twenty, or 58.8% of the 34 respondents who added a comment used it as an opportunity to express personal statements of gratitude or to further highlight their satisfaction with a program, services, or specific providers.

I have had very positive and effective interaction with ILP in [Community] with both of my children. The staff is very considerate, exceptionally helpful and knowledgeable about early childhood skills, development and outreach. I am very pleased.

[ILP] did an excellent job helping our daughter and our family progress in life. The staff was always caring, friendly, helpful and supportive of her and our needs. Very accommodating and available to us.

[ILP] has been wonderful for our son. We started therapy when he was 5 weeks old, and I am sure that the early intervention helped prevent his physical challenges from becoming a serious disability. He is 18 months old now, and is growing and developing normally. His therapist is always willing to discuss new options for his therapy.

Early Intervention Programs as well as the speech and other therapists have all been extremely beneficial to our family. We are very happy with [ILP] and these resources as we have two children in our family that have needed assistance. I would recommend these programs to all who need early interventions for their children. The programs make a big difference in the abilities of the children to grow towards their full potentials.

[ILP Service Provider] does an incredible job at [ILP]. I was so afraid when my boy turned 3, but [ILP Service Provider] made sure that he got enrolled in a program that would really help him. She also worked diligently with his childcare so they would understand what strategies worked best. I can't say enough how wonderful all the staff at [ILP] has been over the last couple of years.

Mixed expressions of satisfaction/dissatisfaction. There were five comments (14.7%) that expressed gratitude or satisfaction, but also dissatisfaction in some respect. Predominantly, these comments indicated problems with transition from ILP services to other programs when children aged out of early intervention. Four transition comments came from respondents served by three different agencies, indicating these were likely isolated cases. The remaining mixed comment expressed dissatisfaction with the physical facility used by the ILP agency.

We were welcomed and well taken care of in the [ILP]. Once we transitioned out of that program and into the EI portion of the school district we have been shunned, outcast, uninvited, unwelcome, uninformed and have had to fight every step of the way and in the end had to pull our child out of his preschool for safety reasons. No one will listen, or do anything to change the situation and so we are just stuck, without our special needs child being able to have a place to learn and grow.

The programs out here in [Community] are incredibly good. The staff are the tops, however, the buildings, inside and out are in great disrepair. I feel funding should be increased to cover needed repairs and thus not take any from the actual programs and staff.

Expressions of frustration and dissatisfaction. Nine comments (26.5%) clearly expressed some level of frustration or dissatisfaction. Some were mixed, but predominantly negative. Six of these comments had a "falling through the cracks" quality about them. These six comments were distributed across four agencies, indicating these were more likely isolated cases as opposed to broad quality assurance problems in single agencies. Three comments indicated families felt that personnel were not qualified or services were not adequate.

[ILP Service Provider] was and is still always helpful. When we moved to [Community] we were sad to lose her as an educator and even sadder to learn that we were not qualified for [Community's] program. We had one visit with an occupational therapist who said our son was in no way qualified for the program but she would send me info on feeding advice. That was the last time I heard from the [Community] program and no information was sent. I have since called [previous ILP Service Provider] and she has taken personal time to assist me with my needs and concerns. We were and are very grateful to her for all of her help.

Living in the bush has made access to services for our child difficult to receive. For many months after he was born, nobody told us there were services we could receive

It would be nice if someone from the office would call at least 6 months after they evaluated the child to see how they are doing.

I felt I knew more than the ILP specialist. I have training in ECE and research all aspects of development (before they occur). My ILP specialist brought me pamphlets from the 70's/80's, which would have been fine, but they did not have current info/updated developments. I was not informed how to opt-out of the program, and felt bad finally telling my ILP specialist "no." All that happened at her visits was a few new toys, a few pamphlets, and chatter. She did not research twin development (which differs greatly from singletons). So, thankfully I knew what I was doing, and was not a parent that relied on ILP services for parenting help.

It was hard to fill out your form. My child no longer participates in infant learning because he "graduated" to the school district program when he turned 3. In Sum. I found ILP well meaning, but not particularly helpful for my child. I am a well educated person who reads a lot and listens a lot. [Another Agency] was much more helpful with information regarding my hearing impaired son. ILP could not provide a speech therapist several times a week (at all actually), which is what he needed. I noticed an immediate improvement upon transition to the school district. When ILP was involved, I had to wait for a speech therapist, private paid by Medicaid, that I took him to 1x/wk. The school district speech therapist works

with him 2x/wk + the teacher also has a speech therapy background. ILP did not hurt, but it was pretty much ineffective....

It is worth reminding the reader that while the mixed and negative comments can be very useful in terms of making general improvements in services, training, and quality assurance, evidence from this survey suggests they did not represent common experiences of families receiving ILP services in 2008. The predominance of comments added to surveys were glowing expressions of gratitude.

Nature of comments by region. It is not valid to judge a region, a grantee, or an agency based strictly on comments added to surveys when there is such a low number of comments. With that caveat in mind, sorting comments by OCS areas (Table 8) shows that no region stands out in terms of the strictly positive/negative nature of the comments respondents made on surveys. There was also no pattern in the content of responses indicating any particular agency had more of a specific problem than any other agency.

Table 8: Distribution of comments by OCS areas

Region: Grantees	Comments				
Region. Grantees	Positive	Negative	Mixed	Totals	
Northern: ACC (Fairbanks), NWA, NSH, TCC, & YKH	5 (56%)	3 (33%)	1 (11%)	9	
Anchorage: PIC	8 (62%)	3 (23%)	2 (15%)	13	
Southcentral: ACC (Copper River & Valdez), BBA, FOC, FCS, HCS, KAN, MSU, SVC	3 (43%)	2 (29%)	2 (29%)	7	
Southeast: CFC, CCK, REA, SER	4 (80%)	1 (20%)	0	5	
Totals	20 (59%)	9 (26%)	5 (15%)	34	

Note: Percents rounded up do not necessarily add up to 100%

Conclusions

It can be concluded from the results of the 2009 survey that there was an overall high level of satisfaction with the EI/ILP services from families receiving Part C services. There were no significant differences within 2009 responses based on race/ethnicity of children or area of residence.

The greatest outcome area strengths were Outcome 1 regarding parental understanding of children, Outcome 5 regarding community access, and Outcome 6 regarding satisfaction with ILP services. There was relatively no change from 2008 to 2009 within Outcome 1, but there were significant increases within both Outcomes 5 and 6. Where these areas saw the most improvements were in opportunities for children to fully participate in community activities (in Outcome 5) and satisfaction with ILPs helping caregivers to know their rights (in Outcome 6).

In Outcome 2 regarding rights and advocacy, there was some indication of improvement from the previous year, especially informing people about rights and services. However, relative to other outcomes, there is room for improvement. Some new items in this area point out

potential concerns about whether or not people are informed they have a right to choose the services they receive, and whether or not they are asked for consent before records are shared with others. Parental knowledge about what they can do if they are not satisfied with their services was also relatively weaker than other satisfaction items.

In Outcome 3 regarding parental ability to help children develop and learn, results were weaker and similar to the previous year. Again, the weakest result within this outcome area indicated caregivers needed much more help in improving their children's behavior.

Similar to the previous survey year, a weak outcome area was Outcome 4 regarding social support. On the one hand, respondents had a high level of access to people they could talk with any time they wanted. On the other hand, the weakest results of the 2009 survey were in families having people in their lives they could call upon to watch their children for a short time, or people they could call upon for other assistance (e.g., transportation, small repairs, etc.).

There were relative strengths and weaknesses within each outcome area. Item results seemed to logically cluster by strength. For example, there were strengths in parents understanding their children's development, being able to detect progress, and knowing how to help their children develop and learn. There were relative weaknesses in understanding their children's special needs, knowing how to help their children behave, and developing plans with a team. There were strengths in the ability of families to do things they enjoyed, as well as in having opportunities for their children to fully participate in community activities.

Comments added to surveys were largely expressions of gratitude and compliments. In the mixed and negative comments, there was an indication that follow-up and transitions from ILPs to preschools and other services were sometimes problematic. These appeared to be isolated cases. That is, there was no indication these problems were symptomatic of any agency.

Issues to consider:

- 1. How can caregivers be helped to build natural, mutual systems of assistance within their social networks? If this is not possible, what else can be done to meet basic needs for occasional childcare and other assistance?
- 2. How can opportunities be increased for family involvement in making plans with teams to address children's special needs?
- 3. How can families be more involved in choosing the services they receive?
- 4. How can parents learn more about their children's special needs and how to help their children to be well behaved?
- 5. How can information about advocacy be communicated more effectively, particularly about ways for families to do something if they are not satisfied?
- 6. If the standard is to always obtain parental consent before sharing records with others, how can ILP compliance with the standard be increased?
- 7. Is there a need to focus more attention system-wide on facilitating better transitions to preschool or other services?

Recommendations for Future Survey Administration

It is recommended that the Alaska State EI/ILP office continue to use the methodologies employed in the 2008 and 2009 surveys, specifically using a randomly selected target group stratified by ILP grantee, and providing for multiple ways to respond to the survey. Reliance on phone numbers as a means to follow up with non-responders seems to be problematic as it appears more young families are replacing land lines with cell phones. It would be helpful if ILP providers were more careful about making sure they correctly entered phone numbers in the database. Often the last two digits are missing. This used to be relatively easy to correct using phone directory resources, but the same resources do not exist for cell phone numbers.

An unrelated research project looking at the impact of CAPTA on the EI/ILP system in Alaska discovered a big discrepancy between data about Native race/ethnicity entered in the EI/ILP database and data entered on the same children in the child protection system. It has been suggested the EI/ILP implement procedures to ensure accurate reporting on this variable. In light of this finding, it seemed the best way to ensure Native representation in the 2009 Family Outcomes Survey was to rely strictly on the random selection process. In this year's survey, available evidence suggested there was appropriate Native representation among respondents.

The survey instrument is becoming more refined. One remaining drawback may be the 4-point Likert scale. This scale was used because it was determined to be culturally appropriate for Alaska's indigenous populations. In terms of research methods, there are at least two potential drawbacks to this scale. First, with only four points, there isn't much sensitivity to detect changes over time. That is, it is more likely that potential improvements will be missed. Second, there is disagreement among researchers about whether or not it is appropriate to use parametric statistics with Likert scale data.

The problem is that each point on a Likert scale is labeled. The argument is that distances between points are inherently disparate. For example, how can one say that the distance between "none" and "some" is the same as the distance between "some" and "most," or that are they the same as the distance between "most" and "all?" And yet, the statistics used to analyze this data assume that the distances between points on the scale are equal.

A more robust approach is to use an interval scale where only the end-points are labeled. For example, using the same language as the current scale, this would mean the end-points might be "none of the time" and "all of the time." Between these two extremes there could be any number of unlabeled points where a respondent could indicate where they fall between the two extremes. It is worth asking ILP service providers with Native heritage if an interval scale makes any sense in the context of indigenous cultures, and if there is any particular way to present such a scale that would make it more understandable.

The disadvantage of making such a change is that it would be a large enough difference to make comparisons with previous years tentative. No statistical tests could be used for comparisons between the different scales. This might not be a huge disadvantage in light of the limitations imposed by the current scale.

APPENDIX A

EI/ILP Introductory Letter to Families 2009 Family Outcomes Survey Instrument





March 10, 2009

Dear Parent or Guardian:

Hello! The State of Alaska Early Intervention/Infant Learning Program is looking for ways to improve early services for children. You can help by completing the enclosed brief survey, which has questions about the services your child received in the year 2008 from one of the community Early Intervention/Infant Learning Programs (listed on the back of this letter). Your participation in this survey is completely voluntary and we hope you will take about 5-10 minutes to give your feedback.

The UAA Center for Human Development (CHD) is an independent contractor collecting the surveys and they will be the only ones to see completed surveys. You can use the enclosed paper survey and return it to CHD in the postage-paid envelope, or you can complete it online at this address: www.alaskachd.org/family. You can also call CHD toll-free at 1-800-243-2199 weekdays between 9am and 4pm and ask to complete the "Family Outcomes Survey" over the phone.

You can be sure that your responses will be confidential. The staff from the State EI/ILP will not see individual surveys at any time. No individual responses will be identified. Your answers will be grouped together with those from other families. By returning a completed survey, you are agreeing to participate.

If you choose the online or phone option, please have this letter handy as you will need the "Survey Verification Number" printed at the bottom to begin the survey. CHD will use this number for two purposes: 1) To check it off a list to ensure that you are not contacted again for this year's survey, and 2) To enter you into a drawing for a thank you gift.

As a thank you for completing the survey, you will be entered into a drawing for a \$25 gift card from a choice of Costco, Walmart, or Fred Meyers. There are 120 families being contacted for this survey, and 10 gift cards will be given out.

If CHD has not heard from you in a couple of weeks, they will give you a call or send a reminder. Please complete the survey no later than April 25. If you have any questions about this survey, please contact Erin Kinavey at (907) 269-3423. Thank you very much for your help!

Sincerely,

Erin Kinavey

Alaska Part C Coordinator

Early Intervention/Infant Learning Program

Survey Verification Number:

Family Outcomes Survey

Please circle the number that best reflects how often the statement is true for you and your family. Circle only one number for each answer. It is okay if you are answering just for yourself (your own opinion or experience) or as a family with shared opinions or experiences.

The statements refer to a "child" but we know some families have more

than one child in the program and in those cases your answers reflect your general or averaged opinions or experiences.	Modilie	Solle diffe	Nostrino	N N N N N N N N N N N N N N N N N N N
 Our child is growing and learning and we understand our child's development very well. 	1	2	3	4
We know most of what we need to know about our child's special needs.	1	2	3	4
3. We can tell if our child is making progress.	1	2	3	4
 We are fully informed about the programs and services that are available for our child and family. 	1	2	3	4
5. We have been asked to give consent before anything from our Early Intervention records is shared with others.	1	2	3	4
We have been informed of our right to choose which Early Intervention services we receive.	1	2	3	4
7. We are comfortable participating in meetings with professionals to plan services or activities for our child.	1	2	3	4
We know what to do if we are not satisfied with any part of our child's program and services.	1	2	3	4
9. We are sure we know how to help our child develop and learn.	1	2	3	4
10. We are sure we know how to help our child learn to behave.	1	2	3	4
11. Our family has worked with professionals to develop a plan to help our child learn new skills.	1	2	3	4
12. Early Intervention has done an excellent job				
helping us know our rights.	1	2	3	4
helping us effectively communicate our child's needs.	1	2	3	4
helping us help our child develop and learn.	1	2	3	4
13. There are people we can talk with any time we want, to help us deal with problems or celebrate when good things happen.	1	2	3	4
14. We have people we can call on for help when we need someone to watch our child for a short time.	1	2	3	4
15. We have people we can call on to help us with things other than childcare (e.g., transportation, shopping, or small repairs).	1	2	3	4
16. We are able to do the activities our family enjoys.	1	2	3	4
17. We have excellent medical care for our child.	1	2	3	4
18. We have excellent childcare for our child.	1	2	3	4
19. Our child has opportunities to fully participate in activities in the community (e.g., playing with others, social or religious events).	1	2	3	4

Continue on other side...

Comments Please note that comments written here go directly to the researcher who is compiling this information. Your confidentiality is protected, so any names or identifying information will not be included with your comments in any summaries or reports. That means that the State EI/ILP office will not be able to answer personal questions or concerns written here. You are always welcome to communicate with them directly using the contact information in the letter that accompanied this survey.

Gift card preference (for drawing): ___Costco ___Walmart ___Fred Meyer

Please return the completed survey in the prepaid envelope to:

University of Alaska Anchorage Center for Human Development Attn: Research & Evaluation 3211 Providence Drive Anchorage, AK 99508-9979

Thank you very much for taking your time to complete this survey!

APPENDIX B

Comments Added to the 2009 Family Outcomes Surveys

APPENDIX B Comments Added to 2009 Family Outcomes Surveys

As comments were typed from surveys, typical spell-check corrections were allowed as long as it was clear what word the writer intended. Some shorthand notations were changed into words, but abbreviations common to the spoken language within this population were retained. For example, "w/o" would be typed as "without," but "OT" and "PT" would be left as written.

Because researchers at the Center for Human Development have a responsibility to protect the identities of survey respondents, reasonable measures were taken to remove identifying information from comments included in this report by replacing it with generic terms in brackets. For example, information that could easily lead back to the identity of a respondent included names of respondents, children, service providers, programs, and communities of residence. Phone numbers or other pieces of contact information were excluded. Within comments recorded here, anything enclosed in brackets represents something replaced or added by the author of this report.

Expressions of Gratitude & Satisfaction (20 or 58.8% of all comments)

All the people we have been involved with in receiving these services have been very knowledgeable.

I have had very positive and effective interaction with ILP in [Community] with both of my children. The staff is very considerate, exceptionally helpful and knowledgeable about early childhood skills, development and outreach. I am very pleased.

I think the [ILP] instructors are awesome.

[ILP] did an excellent job helping our daughter and our family progress in life. The staff was always caring, friendly, helpful and supportive of her and our needs. Very accommodating and available to us.

Very happy with the results of the program.

The programs helped our child's progress and we were glad they were available to us.

The assistance requested and received has been a smooth ride throughout the process. Thank you.

[ILP] has been wonderful for our son. We started therapy when he was 5 weeks old, and I am sure that the early intervention helped prevent his physical challenges from becoming a serious disability. He is 18 months old now, and is growing and developing normally. His therapist is always willing to discuss new options for his therapy.

Everything is working wonderfully.

These programs have been a big help.

- Early Intervention Programs as well as the speech and other therapists have all been extremely beneficial to our family. We are very happy with [ILP] and these resources as we have two children in our family that have needed assistance. I would recommend these programs to all who need early interventions for their children. The programs make a big difference in the abilities of the children to grow towards their full potentials.
- The program has been wonderful in addressing our son's needs. We are very thankful for the services received. Our son just started pre-school and has come a long way in attaining skills needed to be successful as he grows.
- I think [ILP Service Provider] is doing a great job in [Community]. We no longer receive services from ILP. We don't need it anymore. Our little guy is doing just great.
- Thank you for the great program! It has really helped our child and we have recommended the program to others, and another family member is just now entering the program as well. Thanks.
- We received help from [ILP] and that was really good for our child. He is doing much better now. Thank you!
- ILP helped my son succeed. We have had nothing but great experiences. I have 2 other children and had to admit I needed to seek assistance with my 3rd child. He has graduated from physical therapy and other services with nothing but excellent care. Will recommend this program to anyone at any time. We dealt with many people who all responded with care and concern, especially [ILP Service Provider]. She went over and beyond her job requirements to assist us when needed.

Thank you for helping us and my son to develop his skills to grow better.

- Our child is in [ILP]. Our provider is an excellent resource for meeting our needs of our special needs child. We are still learning about special needs and what to expect in the future as our child grows, but our ILP provider will do a great job of helping us with our transitions out of ILP and into his next programs.
- [ILP Service Provider] does an incredible job at [ILP]. I was so afraid when my boy turned 3, but [ILP Service Provider] made sure that he got enrolled in a program that would really help him. She also worked diligently with his childcare so they would understand what strategies worked best. I can't say enough how wonderful all the staff at [ILP] has been over the last couple of years.
- EI/ILP has helped us from the beginning, has shown us how to help our child to develop to where she is now. Now resources are needed to help her now in the future. Thank you

Mixed Expressions of Satisfaction/Dissatisfaction (5 or 14.7% of all comments)

[ILP] was an amazing resource for our family. It was very nice to have the therapists come directly to our home. Our son enjoyed his [Play Group] also. I just wish it went beyond the age of three. I know that the responsibilities transfer to the school district at this age, but our child was not picked up by the school district. We were left alone after his third birthday.

We were very happy with the services received. Our child was over a year behind in speech, when we started, and thanks to our wonderful teachers made tremendous progress. Our child is adopted and ILP made us feel very welcome. Another of our adopted children was turned down by the [School District] because she wasn't "deserving of services" like kids who have lived here all of their lives. ILP never treated our child that way and were always very caring and helpful.

We were welcomed and well taken care of in the [ILP]. Once we transitioned out of that program and into the EI portion of the school district we have been shunned, outcast, uninvited, unwelcome, uninformed and have had to fight every step of the way and in the end had to pull our child out of his preschool for safety reasons. No one will listen, or do anything to change the situation and so we are just stuck, without our special needs child being able to have a place to learn and grow.

I wish the program allowed children to stay in longer, not "aging" them out of the programs but basing the cut off on the child's needs and accomplishments.

The programs out here in [Community] are incredibly good. The staff are the tops, however, the buildings, inside and out are in great disrepair. I feel funding should be increased to cover needed repairs and thus not take any from the actual programs and staff.

Expressions of Frustration & Dissatisfaction (9 or 26.5% of all comments)

Note: Includes "mixed" comments predominantly expressing dissatisfaction.

The concern I had was when not working, we had to remove our child from services due to the cost of gas. Now that our child is in daycare, he has access to the needed services.

I am so thankful for the programs we participated in to help our daughter with her developmental delays. I do have a few suggestions about the process to help decrease the paperwork and have a clear understanding about all the programs before enrolling a child. My daughter will soon be 4 years old but still there is no diagnosis of the "problem". At what point do we stop with the annual appointments/blood work/forms and handle/treat the developmental delay? I truly appreciate the direction/insight/information that we have received along the way, but as a new parent....the system has flaws.

Need more funding! More funding! They are doing great things, but they need to hire more staff, especially therapists. While it is understood that living in the bush makes accessibility harder, there were times we had to wait for our child to be able to receive therapy due to understaffing.

- [ILP Service Provider] was and is still always helpful. When we moved to [Community] we were sad to lose her as an educator and even sadder to learn that we were not qualified for [Community's] program. We had one visit with an occupational therapist who said our son was in no way qualified for the program but she would send me info on feeding advice. That was the last time I heard from the [Community] program and no information was sent. I have since called [previous ILP Service Provider] and she has taken personal time to assist me with my needs and concerns. We were and are very grateful to her for all of her help.
- Living in the bush has made access to services for our child difficult to receive. For many months after he was born, nobody told us there were services we could receive.
- Father does not feel they have received adequate services for their child, that there is no communication or assistance offered and no follow-up for over a year.
- It would be nice if someone from the office would call at least 6 months after they evaluated the child to see how they are doing.
- It was hard to fill out your form. My child no longer participates in infant learning because he "graduated" to the school district program when he turned 3. In Sum. I found ILP well meaning, but not particularly helpful for my child. I am a well educated person who reads a lot and listens a lot. [Another Agency] was much more helpful with information regarding my hearing impaired son. ILP could not provide a speech therapist several times a week (at all actually), which is what he needed. I noticed an immediate improvement upon transition to the school district. When ILP was involved, I had to wait for a speech therapist, private paid by Medicaid, that I took him to 1x/wk. The school district speech therapist works with him 2x/wk + the teacher also has a speech therapy background. ILP did not hurt, but it was pretty much ineffective. Through this month have Medicaid for my son, and the TEFRA gets terminated at the end of this month. The new insurance excludes his hearing and cleft problems, so medical bills will be a problem. I make too much for Denali Kid Care.
- I felt I knew more than the ILP specialist. I have training in ECE and research all aspects of development (before they occur). My ILP specialist brought me pamphlets from the 70's/80's, which would have been fine, but they did not have current info/updated developments. I was not informed how to opt-out of the program, and felt bad finally telling my ILP specialist "no." All that happened at her visits was a few new toys, a few pamphlets, and chatter. She did not research twin development (which differs greatly from singletons). So, thankfully I knew what I was doing, and was not a parent that relied on ILP services for parenting help.

Note: When respondents used the comment space only to write their names, contact information, or simply indicated they had no comment to add, these were not counted as comments.